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# ADD Program Update

Administration on Developmental Disabilities

Administration for Children and Families • U.S. Department of Health and Human Services

## Commissioner's Message



### Collaboration at the U.N. and at Home

I recently returned from a two week stay in New York City. I served as a member of the U.S. delegation to the United Nations participating in the development of an international treaty on civil rights for individuals with disabilities. Our delegation held a briefing on U.S. laws. I had the opportunity to describe the three major grant programs funded through the Developmental Disabilities Assistance and Bill of Rights Act -- State Developmental Disabilities Councils, University Centers on Developmental Disabilities, and State Protection and Advocacy Systems. The audience, including representatives from other countries, found the concepts of Councils, University Centers, and P&A Systems a fascinating example of an infrastructure that has a proven track record for improving the lives of many individuals with developmental disabilities. The audience was especially attentive when I gave examples of **collaboration** among the three types of grantees.

Collaboration is so important. Each of us thinks about it often enough and plans to pursue more of it (including me!). It takes time. It's not easy. It takes many forms. But the key for all of us as this new fiscal year begins is to commit to doing more.

*The American Dream Belongs to Everyone*

I thought it would be worthwhile to briefly describe some of forms of collaboration that may trigger ideas of collaboration -- for you and for me. We could begin by categorizing what we have done through collaboration already and consider how we could build on it. The following index<sup>1</sup> is in the revised MTARS Manual and was recommended by the "Collaboration Subgroup," composed of ADD grantees, Regional Office and ADD staff.

We refer to these forms of collaboration distinctly, but it is important to note that they are not graduations. Instead, they are inter-related steps, which may be conducted in any order or combination, and that build toward true collaboration.

**Communication.** Collaboration always involves communication. We know we are making progress when we share information about our goals with others, with an eye toward building understanding and finding future allies.

**Contribution.** We make further progress when we contribute to and affect what others are doing -- exchanging ideas, providing input, responding to input received, and supporting each other's efforts.

**Coordination.** The next logical step if we are invested in collaboration is coordination. Here we compare needs, share the workload to achieve outcomes, pool resources, and sponsor joint activities.

**Cooperation.** And then there is cooperation. It involves an awareness of others' programs, missions, limitations, and challenges; a willingness to assume complementary roles, eliminate redundancy, and adopt joint goals; and the ability to recognize, accept, and use the strengths and needs of partners, to do more than we could do alone.

**Collaboration.** In its purest form, collaboration encompasses interdependent systems and a shared vision. Partners initiate strategic planning to identify shared goals, outcomes, resources and joint decision-making. We can all aspire to this form of collaboration.

I heard amazing things at the United Nations. Over one hundred nations debated the scope and structure of civil rights for individuals with disabilities; not whether they should be granted, but how they would be realized. If so many nations are willing to work toward that, we here in the U.S. can do a little more collaborating. It will be good for us. It will be good for individuals with developmental disabilities. It will be good for the world.

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<sup>1</sup> Taylor-Powell, E., Rossing, B., & Geran, J. (1998, July). Evaluating Collaboratives: Reaching the Potential. Madison, WI: University of Wisconsin-Extension. [http://cecommerce.uwex.edu/pdfs/G3658\\_8.PDF](http://cecommerce.uwex.edu/pdfs/G3658_8.PDF)

## International Progress in Disability

The last few months have given our developmental disability programs more visibility with international audiences. In the last newsletter we shared our meeting with the seven Iraqi businessmen who want to assist people with disabilities in Iraqi. Thanks to your response to our request for videos depicting individuals with disabilities living and contributing to community life, over 15 videos will be hand-carried to Iraq next week! In June 2004 Faith McCormick and I went to Beijing, China to present at an international conference on special education. Faith talked about America's investment in self-advocacy programs for people with disabilities and I talked about U.S. civil rights laws. We had the opportunity to visit a school for children with intellectual disabilities and historical sites. The numerous professionals and advocates with whom we interacted were very interested in the structure and mission of our DD Act grant programs – so don't be surprised if you get an e-mail from China!



*Children in an exercise class in Haidian District, Beijing Central School for the Mentally Retarded*

## Program Progress

### Network Collaboration

To highlight collaboration in the DD Network, we have selected some examples (from the PPRs, the MTARS reviews, etc.) of collaborative projects taking place and have organized them around the index described in the Commissioner's Message. Though we refer to these forms of collaboration specifically, they are not definitive stages. They are complimentary practices, any or all of which may be involved in a single project. Therefore, some examples may overlap or fit in more than one category of collaboration. Together, they form a basis for setting future goals. The key is that you are the DD Network and your collaborative efforts are having positive impacts in your communities. We salute you for all that you do!

### Communication

In **Virginia** the developmental disabilities network has developed a successful collaborative working relationship. This working relationship enables the network to address both statewide and national issues relating to developmental disabilities. The three Executives maintain effective and consistent communication. They have one regularly scheduled meeting a month, but are in frequent contact to discuss projects and current happenings in the state.

Each of the three DD grantees provides input into the planning process of the other grantees. That is the Director of the P&A provides input into the Council's State Plan and the development of the

UCEDD's Core Grant and the Directors of the Council and UCEDD participate in the development of the P&A's priorities.

The Virginia DD Network collaborates by contributing to each other's newsletters and through membership on each other's Boards or Councils. They jointly participate in activities to improve special education experiences, to train professionals to prevent maltreatment of individuals with disabilities, and to address community living issues inherent in the Olmstead decision.

All three programs participate in Partners in Policymaking. The Council and P&A work together on the Youth Leadership Forum and the Council and UCEDD are sponsors of New Voices. New Voices is an initiative to provide self-advocacy and other system change opportunities to people with developmental disabilities who have been isolated and have not previously participated in such activities.

### Contribution

DD network programs contribute to each others works in a variety of ways. In **Idaho** the Council convened a task force to examine supported living in Idaho. Both P&A and UCEDD were represented on that task force. The task force also served in an advisory capacity to a contract funded by the Council to conduct research on how to amend two HCBS waivers for persons with developmental disabilities to encourage the use of supported living. A report was released in June and is being used, in part, to assist with the development of the self-determination waiver. Recommendations from the report have also been incorporated into changes in billing procedures for supported living services statewide. A copy of the report was also provided to Region X CMS during their Idaho site visit.

The three network components in **Mississippi** are involved in an initiative entitled "Justice for All" that is designed to support individuals with developmental disabilities and people with disabilities who are victims of crime. The Council funds the initiative with the UCEDD. All three serve on a Youth Leadership initiative through a local private/non-profit organization entitled Coalition for Citizens with Disabilities.

The **Alabama** DD Network partners collaborated on the Meet Your Neighbor (MYN) project. The UCEDD served as the lead agency on the video while the Council provided funds for that project. Both the Council and P&A served on the committee and supported the UCEDD during that project. It culminated with a video and an informational packet to make the community aware of what individuals with disabilities can do and how they can be a productive part of a community.

### Coordination

Coordination involves working together on joint activities and/or issues. There are many examples of coordination across the DD Network programs in the States. For example, in **New Jersey**, the Elizabeth M. Boggs Center on Developmental Disabilities, the Protection and Advocacy Agency, and the Council on Developmental Disabilities, together with other partners, collaborated to create a conference, "The Latino Community and Disabilities; Confronting the Barriers." The conference, held on September 17 & 18, 2004, focused on building awareness and strategies for disability service



providers to serve Latino communities, and helping community and faith-based organizations to identify and support the needs of children and adults in their communities.

Each year in **Arkansas**, the Arkansas Governor's Developmental Disabilities Council plans a state conference attended by people with disabilities, family members, direct support professionals and service providers and designed to further the cause of individuals with developmental disabilities. Over the 14 year history of the conference, attendance has grown from 150 to approximately 800 individuals. This year the conference is entitled: "KEYS to COMMUNITY - Unlocking the Door to Independence for People with Disabilities." As with previous conferences the Disability Rights Center (P&A) and Partners for Inclusive Communities (UCEDD) collaborated in the planning of the conference and they will conduct workshops. The conference was held September 16 – 17, 2004 in Hot Springs, Arkansas. The Arkansas network partners are also involved in the needs assessments meeting which takes place in the State prior to development of the Five Year State Plan and annual state plan modifications. They generally hold between three and six public forums/local meetings.

The **Wisconsin** Council on Developmental Disabilities, the Waisman Center UCEDD and the Wisconsin Coalition for Advocacy (WCA) work together as a DD network on many activities. Examples of how they coordinate include joint public hearings, regular joint meetings of Executive Directors, participation in one another's boards and committees, work groups with members across the network, and shared funding and resources. The Wisconsin ADD network has a longstanding involvement with the Survival Coalition, a community-wide initiative, and DAWN, a grass roots self advocacy coalition, in which the Council has taken the lead in supporting activities. In addition, the UCEDD assumed the lead role in the Health Disparities Initiative, for which they coordinated planning for a conference, soliciting state-wide input, and drafting of a summary document. The WCA has the lead role for the network's special education initiatives, advocacy and litigation.

### Cooperation

Cooperation involves an outstanding commitment to a topic or issue. The Council, the P&A and the University Center in **Louisiana** cooperated with one another to initiate and advocate for legislation to create the state's official Olmstead planning group and all three agencies continue to work together in the Olmstead planning process. The Council is assisting in a project of the state's University Center to develop an introductory curriculum for Direct Support Professionals (DSPs) and recommendations for creating a comprehensive system of educational opportunities and career advancement for DSPs.

The DD network in **Arizona** identified that students, family members, and educators have a lack of knowledge concerning the initiation and implementation of adequate and appropriate transition services. The network agencies provide training and support to students, family members, and educators in order for service plans to facilitate self-determination and successful transition outcomes. The Arizona network plans to initiate a public awareness campaign in order to educate the general public on the positive accomplishments and community integration of individuals with developmental disabilities. The Arizona network has identified a lack of qualified related service personnel as a result of the job requirements and the prospective compensation. The agencies plan to identify barriers and implement awareness and systems change activities.

Until recently, the **Utah** P&A, the Disability Law Center (DLC), funded regional offices across the state. These offices were a way of addressing the issues of constituents in rural areas. They were staffed with generalists; however, all the legal issues were best handled out of the Salt Lake City office. The decision was made to close the offices and operate entirely out of the corporate office. The public voiced their concerns when the last office in Cedar City was closed. DLC performed annual needs assessments focused on how best to serve this population. They found that people wanted to be taught self-advocacy skills especially around physical access issues and education. The DD Network has decided to address this systemic issue collaboratively. The Council and P&A will fund a shared position to do outreach, education and training. The UCEDD will work with the staff person to provide the training. A space is being donated by a mental health service provider in the community. This office will serve Southern Utah and is closely located to the two state operated facilities.

### Collaboration

Perhaps the hardest thing to achieve is true collaboration where programs come together around a shared vision. An example of collaboration comes from **Colorado**. In 1997, the Protection and Advocacy Agency, The Legal Center, spearheaded what resulted in a collaborative strategic planning effort across the three programs to move people who were in an institutional setting into the community. In 1997, there were 160 residents at the Grand Junction Regional Center and the network wanted to reduce this number by moving people into the community. The network collaboratively decided to co-sponsor a two-day planning retreat to bring together various representatives from the community at which time they developed a unified effort with the following goal:

*To reduce the number of people with developmental disabilities living on the Grand Junction campus to zero by the end of FY 2000 – 2001, but with the condition that every person who moves off campus:*

- 1. wants to move to the community*
- 2. is safe, and*
- 3. is receiving appropriate, good quality service in the community.*

The Legal Center, the Colorado DD Council, and the UCEDD (JFK Partners) agreed to accept responsibility for the initiative and to form a steering group to move the strategic planning effort forward.

By 2004, there remained just over 60 residents at the Grand Junction Regional Center. Although the network fell short of their intended goal of zero residents, they felt much progress had been achieved through the collaborative effort. Evaluative information from the effort supports this perspective. Surveys responses measuring respondent satisfaction with the initiative indicated overall satisfaction with how the move was planned and how community services were being provided.

## University Centers for Excellence in Developmental Disabilities Education, Research and Services

### ***Assistive Technology***

The Consortium for Handheld Technology is a project of the Partnership for People with Disabilities, the UCEDD in Virginia. The project team trains people ages 14 and older who have acquired brain injuries or autism spectrum disorders to use Palm Pilots and other assistive technology to increase their functional independence in performing everyday tasks. Many participants have shown dramatic improvements in their ability to manage schedules, chores, appointments and transitions at school and in the community.

The Consortium is sponsored by the Commonwealth Neurotrauma Initiative. You can obtain more information including eligibility information by contacting Tony Gentry, M.A., OTR/L, project director, at

Partnership for People with Disabilities  
700 East Franklin Street, 10th Floor  
Richmond, VA 23284-3020  
Fax: 804-828-0042  
(804) 828-7049  
Email [logentry@vcu.edu](mailto:logentry@vcu.edu).

## Program Performance

### **National Aggregates - FY 2003**

#### ***Area of Emphasis: Housing***

State Councils on Developmental Disabilities' Outcome :




- 23 State Councils reported that 4,616 individuals have homes of their choices because of Councils' efforts.
- 16 Councils reported that 444 people moved from congregate setting to homes in the community
- 6,975 persons are active in systems advocacy in housing

Protection and Advocacy Agencies' Outcome:

- 49 P&A's reported that 591 persons obtained or maintained appropriate housing due to P&As' intervention.

*Council and P&A data from the EDS- Program Performance Reports*

University Centers for Excellence in Developmental Disabilities (UCEDD):

-  26 UCEDDs indicated that they engage in housing-related activities
-  20,127 family members/caregivers were reached through housing-related activities
-  9,494 individuals with developmental disabilities were reached through housing-related activities.

*UCEDD data from NIRS*

## Announcements

### ACF Initiative

At the Child Care Bureau's suggestion (with Dr. Horn's approval), ACF signed on as a National Supporting Organization for *Lights On Afterschool!* On October 14, afterschool programs across the country will open their doors to community members, parents and the media in order to highlight the value of these programs. Quality afterschool programs provide a safe place for kids while their parents are working as well as a range of fun activities that promote child and youth development and learning. More than 6000 school-age child care facilities, recreation centers and afterschool programs around the country are expected to participate in this year's *Lights On Afterschool!* event, which is a project of the Afterschool Alliance.

We encourage you to share information about this event (through newsletters, websites, etc) with your grantees or other audiences that might be interested in sponsoring or participating in local *Lights On Afterschool!* events. For more information, please see [http://www.afterschoolalliance.org/loa\\_2004/index.cfm](http://www.afterschoolalliance.org/loa_2004/index.cfm).

### Farewell

ADD and the disabilities network will soon be losing a valued friend. On October 1 of this year Gretchen Menn will retire from the Federal Government. Gretchen has been with the Federal Government for the last 29 years, the last 9 years with the Administration on Developmental Disabilities. We will miss her hard work and dedication. We wish her well.

### 2003 Series Publications

ADD has released two electronic program fact sheets and is preparing to release one additional program fact sheet and the new ADD Brochure. The materials will be distributed to ADD staff, Regional office staff, and grantee executive directors, as soon as they become available.



## ADDED Resources

### Breast Health Handbook

The Wyoming Institute for Disabilities has created a handbook, *Women First: Breast Health for Women with Developmental Disabilities*, designed to provide women with developmental disabilities basic information about breast health. It includes a calendar that can be used to track monthly self exams and yearly visits with a personal health care provider.

For more information about the project and for a downloadable version of the handbook, go to <http://wind.uwyo.edu/breasthealth/>

### California Council's On-line Library

The California State Council on Developmental Disabilities is EXTREMELY pleased to announce the arrival of the SCDD Online Library.

The SCDD Online Library offers more than 3,000 resources specific to the field of developmental disabilities. Search all the California State and federal laws that relate to developmental disabilities and access hard-to-find data, research, and reports. The on-line library makes it easy to find directories, journals, and a large collection of videotapes. The library is non-circulating. Please contact the publisher to obtain the items.

The SCDD Online Library features training materials and resources developed by Community Program Development Grants sponsored by the Council. Searches can be conducted by topic, such as law enforcement training, telemedicine, or safety awareness or by looking under the section on California Council Grants and Projects. Each listing provides information on obtaining the item and several resources are available in PDF (portable document format) online. Please visit <http://www.scdd.ca.gov> and check it out!